Genetic Lingua: Speaking Genetics

Suzanne Belinson Executive Director, Center for Clinical Effectiveness Office of Clinical Affairs



GENETIC LINGUA

SPEAKING GENETICS

Working Group Members

- Suzanne Belinson (BCBSA) Co-Chair
- Carla Easter (NIH) Co-Chair
- Bob Wildin (NIH)
- Ann Karty (AAFP)
- Temese Szalai (Madarka)

SPEAKING GENETICS HISTORY

- Formed last year
- Meet twice a month
- Finalizing 2015 scope
- Addition of an analytical linguist and associated data science team & technology
- In the data collection phase

SPEAKING GENETICS GOALS

- Vision- Uniformly accessible language of genetics
 - Build a meta-language that takes complex concepts in genetic medicine and distills them into a fluid, accessible and comprehensible vocabulary and system of expression that will work across the communication landscape of genetic medicine.
- 2015 Goals
 - Identify communication buckets
 - English only focus
 - Data analysis
 - Identify common language elements in use
 - Prioritization
 - Propose recommendations for prioritized language elements

SPEAKING GENETICS COMMUNICATION

- Consumer space
- Provider :: Patient communication
- Payer :: Patient communication
- Provider :: Lab communication
- Advocacy Groups:: (Patients, Providers, Government, Funders, Patrons, etc.)
- Research

SPEAKING GENETICS NEXT STEPS

- Gather and Analyze Data
- Prioritize communication items for language construction
- Develop initial meta-language constructions for evaluation
- Evaluate through testing, including diverse audiences

SPEAKING GENETICS ASK

INVOLVEMENT FUNDING

Thank You

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